Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth
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Monitoring and Benchmarking eHealth in the Nordic Countries

Christian NØHR[a,1], Sabine KOCH[b], Vivian VIMARLUND[c], Heidi GILSTAD[d], Arild FAXVAAG[d], Gudrun Audur HARDARDOTTIR[e], Hege K. ANDREASSEN[f], Maarit KANGAS[g], Jarmo REPONEN[g], Pernille BERTELSEN[h] Sidsel VILLUMSEN[h], Hannele HYPPÖNEN[i]

[a] *Health Informatics and Technology, University of Southern Denmark*
[b] *Department of Learning, Informatics, Management and Ethics, Karolinska Institute*
[c] *Linköping University, Department of Information and Computer Science (IDA)*
[d] *Health Informatics Research Group, Norwegian University of Science and Technology*
[e] *Directorate of Health, Iceland*
[f] *Norwegian Centre for e-health Research*
[g] *Research Unit of Medical Imaging, Physics and Technology, University of Oulu*
[h] *Danish Center for Health Informatics (DaCHI), Aalborg University, Denmark*
[i] *National Institute for Health and Welfare, Information Department, Helsinki, Finland.*

Abstract. The Nordic eHealth Research Network, a subgroup of the Nordic Council of Ministers eHealth group, is working on developing indicators to monitor progress in availability, use and outcome of eHealth applications in the Nordic countries. This paper reports on the consecutive analysis of National eHealth policies in the Nordic countries from 2012 to 2016. Furthermore, it discusses the consequences for the development of indicators that can measure changes in the eHealth environment arising from the policies. The main change in policies is reflected in a shift towards more stakeholder involvement and intensified focus on clinical infrastructure. This change suggests developing indicators that can monitor understandability and usability of eHealth systems, and the use and utility of shared information infrastructure from the perspective of the end-users – citizens/patients and clinicians in particular.

Keywords. Health Information Technologies, National eHealth policies, Quality Improvement, Benchmarking.

Introduction

The former governor of New York, Mario Cuorno described his mother's rules for success as (a) figure out what you want to do and (b) do it [1]. These are pretty much the same rules that national strategies for developing and implementing eHealth systems must follow. Policy makers must identify the need, conceptualize a strategy capable of alleviating that need, and then implement it. Determined development work of both social and technical systems considering requirements of key stakeholders precedes implementation, and local context sensitive implementation strategies need to be developed.

[1] Corresponding Author, Christian Nøhr, e-mail: cn@mmmi.sdu.dk

Worldwide, anticipated impacts for information and communication technologies (ICT) include improving patient safety, increasing the quality and efficiency of care, reducing administrative and operating costs of the health care system, and enabling new models of health care [2]. Many countries have developed plans for in ICT investment in order to achieve strategic goals. However, less effort has been exercised in developing indicators to assess to what extent these strategic goals are accomplished. To develop indicators and implement monitoring activities within one health system is not trivial, and to do this across different countries is even more complicated. Differences in what constitutes for instance an Electronic Health Record (EHR) varies considerably, and different sampling techniques give different statistical basis and limit cross country comparability [3].

Indicators can be developed to monitor adoption, use, or impact on service delivery and quality of care [4]. The ultimate goal would be to measure the impact on service delivery and quality of care directly to read the return on investment (ROI). However, effects are consequences of sequences of actions. Furthermore, due to the complexity of health care provision that involves a wide range of actors, it is difficult to determine the contribution of a particular technology to a specific outcome. Adoption rates are the most simple to develop and use as indicators. However, it becomes irrelevant to quantify availability or access to specific eHealth systems as the implementation approaches saturation. Then it becomes more interesting to quantify the actual use, usability and utility of specific systems or specific functionalities. Here both the citizen's perception of and their actual use of eHealth can, as they are the end users, inform on the degree of success in reaching the strategic goals. It is obviously not possible to monitor all functionalities due to the sheer amount of these. The national strategies provide guidance as to which functionalities are the most important to monitor.

National policy documents have a limited timespan – from three to five years is common, and often they are adjusted after a two-year midway evaluation. It is also seen that health policy makers seek to let evidence inform policy documents, as seen in [12]. This observation applies both to the making and to the assessment of policies.

Developing and implementing eHealth systems, such as a patient record system, are - according to one of the pioneers in health informatics Morris Collen - "a more complex task than putting a man on the moon" [5]. Once developed and implemented, eHealth systems become part of an infrastructure that is supposed to serve the interests and objectives of multiple stakeholders in a myriad of contexts of use, e.g., computerized physician order entry systems, home tele-monitoring, comprehensive interdisciplinary clinical workstations, and collection of health data for secondary use. Furthermore, various health care professions with individual work practices are using eHealth systems for different purposes, and the same counts for citizens with different levels of health literacy and eHealth time (e.g. versions 0.1 to 2.0) as do the usages and contexts of use, and different clinical specialities call for appropriation to their specific knowledgebase.

Therefore, the complex task of developing and implementing integrated eHealth systems in the entire health care sector is hardly achieved within the lifespan of a single strategy. A rational approach for improvement between strategies would be to evaluate the progress achieved by each strategy and to acknowledge both achievements and insufficiencies in a closed learning cycle.

Ideally development and management of strategies should happen in a cycle as shown in figure 1. Strategic goals are often formulated with respect to previous strategies, accomplishments from the past, what contemporary technology now enables and what is

envisioned in current health policy. The initial strategic goals form the basis for achieving consensus and engagement that can produce a plan for how to reach operational goals. The operational goals should initiate processes of innovation, development, and consolidation of the technical (and socio-technical) elements that will build the infrastructure development. The infrastructure will support business improvement through further innovation, development, dissemination, and implementation. Ideally the achieved improvements should be evaluated and assessed to determine to what extent the strategic goals have been achieved.

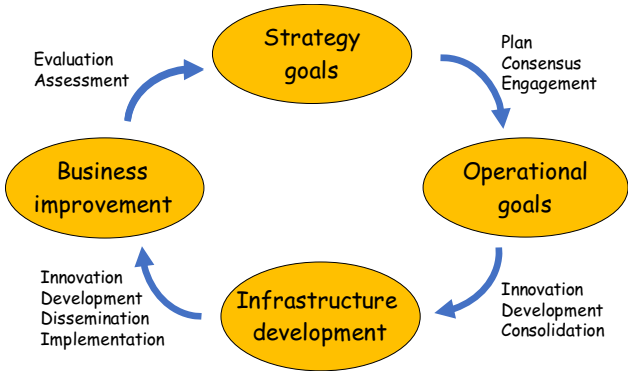

Figure 1. Life cycle of a national strategy for eHealth

For six years, the Nordic eHealth Research Network (NeRN) has strived to develop, test and assess a common set of indicators for monitoring eHealth in the Nordic Countries, Greenland, The Faroe Islands, and Åland. The overall goal is to support national and international policy makers and scientific communities to develop Nordic welfare. NeRN has published their work in more than 20 scientific publications [6]. These publications report details about a methodology to generate eHealth indicators and benchmarking results of 49 common Nordic eHealth indicators for which data were available for at least some of the Nordic countries. Several challenges and problems have been discovered through this work. This paper reports on one of the issues that the NeRN network has worked on: How have the national policies changed from 2012 to 2016 and how does that effect the need for indicators?

1. Materials and methods

Based on two consecutive policy analyses we were able to do a comparative analysis of Nordic eHealth policies from before 2012 and policies from 2012 onward. The first policy analysis is reported in previous publications [7]. The results of the second analysis based on [8–12] are reported in this paper.

Contents of these current eHealth policy documents were analyzed to identify their key objectives and to explore how policy main target areas have changed between the two studies. Policy characteristics from the two streams of research were compared. The Swedish, Norwegian, and Danish documents were analyzed in their respective native languages. The eHealth strategies from Iceland and Finland were analyzed using the official English version. The text annotation tool HyperResearch (ReasearchWare, Inc.) was used for the analysis, where sentences and sections with statements about: a) motivation for policy, b) main strategic targets, c) actors and players, d) measures, e) plans,

and f) stakeholders involved, were tagged with a code. The codebook from 2012 was used as a template for the second study, but extended with updated concepts. In a second coding round, the codebook was condensed and overlapping codes were merged. The first and second coding rounds were performed by researcher "AF" and the results were reviewed by researchers "CN" and "SV". Disagreement of the coding was discussed in each case to reach consensus.

2. Results

The Nordic countries are among the first in the world to develop and implement integrated eHealth technologies. Because of the publicly financed health care systems, the initiatives have reached a high coverage on a national basis. However, this does not mean that the different health care providers have implemented the same systems or contracted with the same vendors. Instead, use of various standards have enabled different actors to communicate structured data within certain limits.

The analysis of the current eHealth policy documents revealed seven key strategic targets common to all the Nordic countries: 1) Using eHealth to empower and activate citizens, 2) making citizens' digital interface his/her preferred channel for interacting with the healthcare system, 3) making health services more integrated and digitally available, 4) making eHealth systems more usable for the clinician and citizen end-users, 5) improving eHealth literacy among the citizens, 6) reaping the economic benefits of investments in eHealth systems and infrastructures, and 7) improving healthcare services by building and implementing eHealth systems and services.

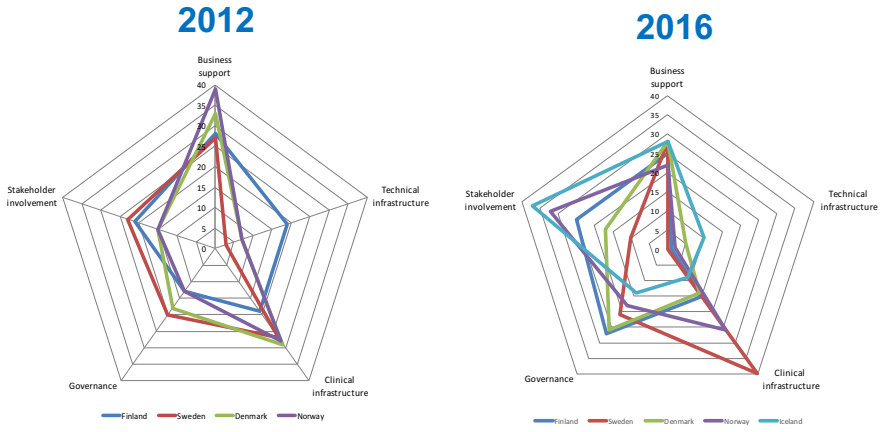

Figure 2. National eHealth strategy profiles from 2012 and 2016 [13]

The main changes in strategic targets are depicted in figure 2. The scale shows the number of text segments belonging to the specific policy items in percentage of the sum of segments coded for each country. There is a shift from a main focus on technical issues, such as technical and clinical infrastructure, towards governance and stakeholder involvement. Also, the relative role of business support has decreased. However, Sweden still has a significant emphasis on clinical infrastructure and the technical infrastructure has more importance in Iceland than in other countries.

3. Discussion and conclusion

The changes in the focus of national eHealth policies in the Nordic countries indicate that benchmarking should be conducted to reflect the achievements in availability, update-ability, trustability and understandability of eHealth services from the perspective of clinicians as well as patients. The dominating tools for measuring understandability and usability of eHealth systems has been used on an individual level for some time, whereas several challenges remain to obtain a generic measure for a national level that can be used to compare the Nordic countries. Further there could be a need to support quantitative measures with qualitative inquiries on selected cases to allow for a deeper understanding of the national practices.

As the availability for many eHealth services approaches 100%, it is also required to develop indicators that reflect the actual use. It could be tempting to collect and compare log data harvested from national log files. However, when confronted with the specific context in the different systems it has proven challenging to define a common set of indicators for monitoring the practical use of eHealth [3].

A third focus for the development of indicators should reflect the design, maintenance, availability, use and utility of shared information infrastructure from the perspective of the end-users - clinicians in particular but also patients when in contact with health care providers, their relatives, and citizens using eHealth applications to promote their health.

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